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Adults on the Autism Spectrum: A Quality Improvement Project to Develop a Patient-Centered Nursing Care Guideline for the Acute Care Setting

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Abstract

Background: Incidence of autism spectrum disorder is increasing. Current prevalence rate is 1 in 59 people, which translates to roughly 1% of the U.S. population. These adults have higher rates of epilepsy, gastrointestinal disorders, obesity, cardiac dysfunction, and mental health disorders. Healthcare system utilization is resultantly greater than their neurotypical counterparts, coupled with longer lengths of stay and decreased patient satisfaction reports.

Purpose: Most nurses report little to no formal training about the disorder or how to develop interventions sensitive to the needs of this population yet are crucial care givers to ensure patient-centeredness. A guideline to acute care for adults on the autism spectrum will be created to assist nurses and develop competency.

Methods: The Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) has developed a toolkit to assist primary care providers. Using AASPIRE as the basis, an acute care guideline will be developed and tested in a large academic medical center, piloted on 2 units. The guideline will be merged into the online nursing clinical practice manual. Nursing staff (registered nurses and nursing assistants) will have an educational intervention. A pre-test based upon the Autism Knowledge Survey will be administered to ascertain baseline knowledge of ASD and comfort in caring for these patients. A post-test will be sent 1 month after the intervention to see if knowledge and comfort level has improved.

Results: Overall, the post survey results were improved from the pre-survey. The staff demonstrated increased knowledge of ASD and a significant increase in their comfort level in caring for these patients.

Conclusions and Implications: Knowing how to care for adults with Autism Spectrum Disorder is critical as the prevalence continues to increase. By adapting care to the special needs of this population, it is hoped that they will report improved patient experiences and perhaps decrease overall lengths of stay in the acute care setting

Keywords: acute and critical illness, adult and older adult, evidence-based practice, quality and safety, social determinants of health

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Problem Description

The number of people diagnosed with Autism Spectrum Disorder is increasing. The Centers for Disease Control and Prevention (CDC), began tracking the prevalence of children aged 8 and over with ASD in 2000 after a small study completed by the CDC in 1998 found much larger prevalence rates than had previously been reported in the literature. They established the Autism and Developmental Disabilities Monitoring Network to track the occurrence of this condition. The first surveillance completed between 2000-2002 reported that 6.7 out of 1000 children (1:150) had an established diagnosis of Autism. Ten years later, these numbers more than doubled. In 2010, the prevalence was reported to be 14.6 per 1000 (1:68). The latest survey, which was completed in 2014, estimates that 168 children out of 1000 (1:59) have ASD (Baio et al., 2018).

Much of the literature and research focuses on children as the majority of whom will be diagnosed in this developmental time frame (Murphy et al., 2016). But these children will spend most of their lives and receive much of their healthcare as adults. A disorder once to only be thought of as affecting children is quickly becoming a disorder of adulthood (Mandell, 2013). It has been well documented that adults on the spectrum have increased morbidity and shorter life spans (Bishop-Fitzpatrick, 2017). These adults are more likely than their neurotypical counterparts to have mental health disorders, epilepsy, cardiovascular disease, dyslipidemia, hypertension, diabetes, obesity, digestive system disease, sleep disorders and cancer (Mason et al., 2019).

But despite the need for healthcare services, adults on the autism spectrum face challenges navigating access to care. Adults with ASD are more likely to report dissatisfaction with their health care providers. Many avoid making appointments and depend upon the emergency department for a great deal of their care (Mason et al., 2019). There have been multiple studies that have looked at the cause of this disparity. ASD adults report that the top barriers are personal emotional regulation, sensory sensitivity, patient-provider communication, and healthcare navigation. (Raymaker et al., 2017). Currently, much literature focuses on primary care and routine services. Since most adults will utilize these services on a routine basis, it is understandable why the bulk of the research has been directed in this area.

Additionally, sometimes adults with ASD will need hospital services. As previously mentioned, ASD adults utilize the emergency room frequently and some will need to be hospitalized. The few studies that have been published cite similar findings as primary care settings with some additional stressors. Unfamiliar settings, lights, sounds, odors, and frequency of touch have been reported to cause distress. In addition, the lack of predictability of care and lack of flexibility can be challenging for the patient on the spectrum. There is little to no accommodations for the patients' disabilities (Muskat et al.)

A major reason for this lack of accommodation is knowledge deficit. Autism Spectrum Disorder can be difficult to understand. Although patients may have similar presentations, each patient will have their own strengths and limitations. Most healthcare providers report little to no formal training in ASD. A recent study in the United Kingdom reported that close to 40% of physicians reported limited confidence in identifying and managing autistic patients (Unigwe et al., 2017). Physicians across the world report a lack of awareness in how to care for these

patients and cite no readily available evidenced based interventions for primary care and hospital settings (Murphy et al., 2016).

Physicians are not the only ones to report knowledge deficits on how to care for autistic adults. Nurses also report low competency levels in caring for this population. They report a lack of knowledge regarding how to communicate and deal with certain behaviors. Few nursing programs provide any education other than in the pediatric population. (Gardner et al., 2016). Nurses and other health care workers will encounter autistic patients in all health care settings across the lifespan. Clinicians need tools that will help them to provide truly patient-centered appropriate care.

Available Knowledge

Autism Spectrum Disorder is a developmental condition that affects communication and behavior. Per the *Diagnostic Statistical Manual of Mental Disorders* (DSM-V) ASD is a sensory and information processing disorder. It is described as a spectrum since the symptoms fall on a continuum. Some people have mild symptoms and others have severe symptoms. The condition exhibits difficulty with communication, social interactions, and restrictive, repetitive behaviors. These traits and actions cause those on the spectrum to have trouble in their personal, school, and work lives. (American Psychiatric Association, 2013).

A study conducted in 2015 best summarizes the challenges that autistic patients face in the healthcare system. The reasons can be grouped into three areas:

- System related factors
 - Availability of supports
 - Complexities of the healthcare system
 - Stigma about autism

- Patient-level factors
 - Verbal communication skills
 - Sensory sensitivities
 - Slow processing speed
 - Atypical non-verbal communication
 - Challenges with organization
- Provider-level factors
 - Knowledge about autism in adults
 - Incorrect assumptions about patients
 - Use of accessible language
 - Openness to providing other accommodations
 - Skill in incorporating supporters (Nicolaidis et al., 2015)

Systems

Most autistic adults have some level of impairment in executive functioning. This is the ability of humans to plan, focus attention, remember instructions, and multitask. Navigating the healthcare system requires this ability to be successful in finding and establishing care. Studies have found that just the act of knowing where and how to get care is overwhelming and many cannot get past this step (Mason et al., 2019). In addition, there are limited providers experienced in the care of autistic adults, so wait lists are long. The intake process often is not so friendly (Vogan et al., 2017).

Additionally, healthcare systems lack the flexibility and supports needed by this group. Patients can be moved room to room in order to accommodate the needs of the system. Rooms may change due to the needs of other patients such as roommate issues, new identified contact

precautions, and physician team preference to name a few, but this can be traumatic for the autistic patient. Furthermore, there are not many sensory friendly rooms for these patients to be seen. The lights are bright and the atmosphere is loud which can be problematic. Routines such as vital signs and lab draws are not usually altered to accomodate the needs of these patients (Muskat et al., 2015).

Patients

ASD patients face many challenges in healthcare: unfamiliar environments, sensory insensitivities and communication issues can be the most problematic. Sensory issues may be affected by lights, sounds, smells, and touch. In the hospital, there are bright lights, loud and unusual sounds, and unpleasant smells (Mason et al., 2019). There is also much touching in healthcare. Patients are frequently touched in examinations, testing, and routine care (Muskat et al., 2015). These inputs can cause increased stress and anxiety. Patients may over or under react to these stressors. Thus, there may be unwanted behavioral issues (Zannotti, 2019).

Communication problems are many. Some may lack the verbal communication skills necessary to participate in care. ASD adults may need more time to process the information and more time to respond (Raymaker et al., 2017). They may not always be able to articulate their symptoms or pain level. Due to literal thinking and the inability to recognize social cues, abstract concepts used frequently in this setting cannot be applied to these patients. Pain scales have little meaning and some adjectives such as stabbing or burning can have a different connotation (Zannotti, 2019).

Providers

Communication issues complicate care not only for patients, but also for providers. Providers may not be aware that they may need to alter their communication style to be

understood. They also may not know that ASD patients may require more time to process information given and more time in which to respond. Providers may inadvertently think that the patient lacks intellectual ability to understand thus applying the stigma surrounding autistic patients. ASD patients may need to write notes to retain what is being said to them. Patients may not be given this luxury in the fast-paced healthcare setting (Mason et al., 2019).

To complicate the matter even further, some ASD patients may be completely non-verbal but mentally intact. They can communicate through the written word or pictures, but many times healthcare providers will not take this into consideration. They do not involve the patient in the conversation deferring to speak with their companion and disregarding that they have capacity to make their own decisions (Mason et al., 2019).

Hospital staff may also confound issues by not understanding some basic needs. Lack of consistent caregivers can be stressful. Rounding of care teams brings too many people into the room and can be upsetting. Not recognizing the expertise of the patient or caregiver can cause further frustration (Muskat et al., 2015).

Provider Knowledge

No two people with autism are alike. Without a standard presentation, it is not surprising that healthcare workers do not always feel prepared to care for these patients. Kaiser Permanente, a large health care system in California, surveyed health care providers across the system; the results were sobering. Approximately 90% of the respondents rated their confidence in caring for ASD patients as poor to fair. In addition, 80% report not having the tools or training that would assist them with this population. The researchers were dismayed by some of the comments they received. Many health care providers reported that they did not care for any ASD patients because they do not work with pediatric patients and some stated they had no autistic patients in

their practice. Through the study it was found that indeed these providers did care for patients on the spectrum, yet they had no idea (Croen, 2013).

Another study, like the Kaiser work, surveyed 350 adult internal medicine providers. In a self-reported questionnaire, the overall themes again demonstrated the perceived lack of knowledge and ability to care for adults with ASD due too little to no training and the desire for more knowledge. These providers felt that the lack of knowledge was a barrier to providing competent care (Bruder et al., 2012). A third study found similar results with most stating they had little to no training and have limited confidence in their ability to diagnose, treat, and manage this population (Unigwe et al., 2017).

It is no surprise that these deficits exist. It has been found that medical schools, nursing schools, and hospitals provide little to no training except in pediatrics. Caregivers report low knowledge in how to teach ASD patients, how to communicate effectively, or how to understand the safety needs of these people (Nicolaidis et al., 2015).

Tools for Understanding

Much of the literature focuses on pediatrics. There is much literature to support the pediatric providers to understand the varying needs of the autistic child in the healthcare setting. Whereas healthcare providers for adults lack any information to help guide care. In response, a partnership of academic researchers, autistic adults, family members, healthcare and disability providers (AASPIRE) came together to develop an online toolkit for healthcare providers and autistic adults. This work was funded by the National Institute of Mental Health. The toolkit was tested by 259 autistic adults and 51 primary care providers. Overall results were positive. There was strong content validity and adequate test/retest stability with more that 94% of participants reporting that the toolkit was easy to use, important, and useful. In pre/post intervention

comparisons, the mean number of barriers decreased from 4.07 to 2.82 $p < 0.0001$. Healthcare self-efficacy increased from 37.9 to 39.4, $p = 0.02$ and satisfaction with primary care provider improved from 30.9 to 32.6, $p = 0.03$. Patients reported that the toolkit helped them to clarify their needs and enabled them to self-advocate. In addition, 97% of primary care physicians rated it as moderately to very useful. (Nicolaidis et al., 2016)

Like the AASPIRE work, a toolkit was developed by a collaborative from Massachusetts General Hospital. Due to limited evidence dedicated to hospitalized adults, an expert panel was convened to develop pathways and guidelines for this population. This expert panel included pediatric and adult therapists, nurses, physicians, parents, and patients. Based upon evidenced-based interventions proven effective in pediatrics such as the development of specialized inpatient care pathways, augmentation of communication through partnership with patients and their families, avoidance of environmental triggers, reduction of non-essential testing and monitoring, and use of acute care plans the panel developed interventions for acute care. Although not formally tested statistically, the material was piloted on dedicated units and elicited positive results. (Carter et al., 2017)

Rationale

The concept of patient centered care is not new. In 2001, the Institute of Medicine released its landmark report defining quality care (Tzelepis, Sanson-Fisher, Zucca, & Fradgley, 2015). Key aspects of high-quality care are described as person centered. All individuals have the right to be treated with dignity and respect. This means simply listening to, informing, and involving patients in their care and being respectful and responsive to individual values and preferences. When care is person-centered health care utilization and outcomes are improved (Larson et al., 2019).

Patients and their families need to be directly involved in planning care. Family perspective is critical in filling in gaps of information that the patient themselves may not be able to provide. ASD adults are more likely to have unmet physical and mental health needs. They have higher rates of disease, higher utilization of health care services, and lower patient satisfaction than their neurotypical counterparts (Mandell, 2013).

As core caregivers in the acute care setting, the nurses role in patient outcomes is significant and guidelines to ensure competency is imperative. The investigator seeks to develop a nursing care guideline to facilitate adequate care to the ASD population and their families. The nursing care guideline will include a questionnaire that will be completed by the individual or by the caregiver. This questionnaire will be adapted from one currently in use at Massachusetts General Hospital. The survey will include questions regarding triggers and routines that have worked to keep the patient's anxiety low. When ASD patients have increased anxiety, unwanted behaviors may occur (Zannotti, 2019). The actions may cause the patient to be unnecessarily restrained either chemically, physically, or both (Carter et al., 2017).

Legally, per the Americans with Disabilities Act, hospitals must make accommodations for disabled patients. Though despite this mandate, most facilities do not or are unable to make these accommodations possible. The creation of the nursing care guideline will give the staff tools to provide this necessity. (United States Department of Justice, 2017)

Specific Aim

The aim of this work is to improve the patient care experience for adults on the autism spectrum. In order to accomplish this goal, a nursing care guideline that provides an overview of the disorder as well as strategies to deal with certain issues and behaviors was developed. This guideline went through the committee approval process and was adopted and placed in the online

Nursing Clinical Practice Manual. An educational intervention was designed for direct care nursing staff. The education involved a review of the guideline and how to access from the online portal. Between January 6-10, 2020, 75% of the staff would receive the in-service. Knowledge level and comfort in the care of this population would be tested immediately before and one month after the intervention. By March 1, 2020, at least 50% of those who attended would submit a post survey follow-up.

Methods

Context

Brigham and Women's Hospital is a large academic medical center in Boston. It is in close proximity to Boston Children's Hospital and as a result does not have a pediatric service other than the neonatal intensive care unit. Therefore, there is a pervasive feeling that the facility does not have a large percentage of patients that have a history of autistic spectrum disorder. As has been stated, the national prevalence is roughly 1% of the U.S. population. So it can be assumed that there are many patients treated at the facility who are on the autism spectrum.

Intervention

A nursing care guideline was created based upon the AASPIRE toolkit. This guideline includes critical domains for awareness and treatment:

- Overview of Autism Spectrum Disorder
- Communication and Interaction Interventions
- Sensory Issues and Interventions
- Body Awareness
- Planning and Organizing
- Exams and procedures

- Patient/Caregiver checklist to inform care

After the guideline was written, it was vetted through the various approval committees within the hospital. The work was reviewed by the Policies and Procedures Steering Committee and approved by the Nurse Executive Board. It was then entered into the online Clinical Practice Manual under the *Guidelines* heading.

The guideline can be utilized for any patient who is seen in the Emergency Department or admitted to an inpatient area with an ASD diagnosis. The disorder must be disclosed in the medical record or by admission of this information by the patient/caregiver. The assigned nurse will be able to access the guideline from the online Clinical Practice Manual.

The ASD guideline was piloted on two medical units: Tower 14AB and Tower 14CD. The pilot consisted of a staff education intervention. The staff included nurses and nursing assistants. They were given a 30 minute in-service which included an overview of Autism Spectrum Disorders, prevalence in inpatients at Brigham and Women's Hospital, and a review of the guideline for care. This in-service also included a review of instructions on how to access the guideline. There were 8 separate educational opportunities: 4 on the day shift, and 4 on the night shift. In total, 37 staff members received the education.

Study of the Interventions

The intervention was assessed by having the participants complete a survey immediately before and one month after the education. Participants remained anonymous. The only identifying question surrounded job role. More than half chose to not answer this question therefore it was eliminated. The results were compared to determine if the intervention had any impact on knowledge or comfort level in caring for these patients.

Measures

Prior to the educational intervention, each participant received a paper copy of the Autism Knowledge Survey (AKS) (See Appendix A). The AKS is a 21-question survey that focuses on the stigma that surrounds this disorder. The survey has established high levels of reliability and validity and has been used in multiple research studies (Harrison et al., 2017). In addition, two questions were added that assessed comfort in caring for ASD patients and likelihood of utilizing tools in that care. The AKS survey was modified in the following ways. Any mention of “child” was changed to “people” as there are currently no tested tools that inquire about knowledge of ASD adults. This modification was necessary. The three identifying questions were removed and replaced with one question that identified role: RN/PCA. The two narrative questions at the end were also removed as they deal with diagnostic criteria which neither group is expected to know or will need to know in the future. Since the survey was created in 1987, one question needed to be changed due to wording. The phrase “mentally retarded” was changed to “intellectual challenges” (Stone, 1987).

One month after the intervention, an electronic survey was distributed to all nurses and nursing assistants who work on Tower 14ABCD. The *Survey Monkey* platform was utilized to maintain anonymity and sent to their *Partners* email address. Since the survey was dispersed to all staff on those units, one additional question needed to be added to determine if the respondent participated in the intervention. The remaining questions were those that were included in the initial survey. Results from the pre- and the post-survey were compared.

Analysis

The results were compared using two methods. Although surveys that use Likert-like questions are generally analyzed using a paired t-test, this statistical test could not be used. The

data was not derived from the same participants who had been measured at two time points. The first type of analysis was conducted using *Microsoft Excel*. The percent change of each survey question was determined. These figures were compared to determine if the intervention had any effect (+/-) on knowledge level or comfort in caring for these patients of the participants.

The data was then reanalyzed using independent t-test comparisons. This method is an inferential statistical test that determines whether there is a statistically significant difference between the means in two unrelated groups. This test was completed by using *Microsoft Excel* and checked for accuracy through using the *JMP* statistical software program.

Ethical Considerations

The project was presented to the Nurse Scientists Council prior to implementation. They determined that IRB was not required for this quality improvement project as no patients or patients' records were accessed and no new knowledge was generated.

Results

In total, there were 37 participants in the intervention. This equates to roughly 30% of the staff. This was much lower than the expected goal of 75% attendance. The education was completed by January 10, 2020 as planned and survey results were collected till March 1, 2020. Twelve people returned the post-survey but 6 had to be eliminated since the respondents indicated that they did not attend the in-service.

Overall, the intervention appears to have been successful in improving the knowledge base and comfort level of the staff in caring for patients on the Autism spectrum. The AKS survey asks participants to rank their level of agreement or disagreement with each statement using a 1-5 Likert scale. A low score is means agreement with the stereotype and a high score

indicates disagreement. Therefore, a low score is indicative of a knowledge deficit. Overall, the pre-intervention scores were much lower than the post intervention values (Table 1).

Table 1. Autism Knowledge Survey

Questions-Likert Like 1=Completely Agree 2=Slightly Agree 3=Neither agree nor disagree 4=Disagree Slightly 5=Completely Disagree	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey
	1		2		3		4		5	
1. 1. Autism is an emotional disorder	8.10%	0.00%	27.00%	50%	16.20%	16.70%	21.60%	0.00%	27.00%	33.30%
2. 2. Emotional factors play a major role in the etiology of Autism	24.30%	16.70%	13.50%	16.70%	29.70%	33.30%	16.20%	16.70%	13.50%	16.70%
3. 3. Autistic people are deliberately negative and non-compliant	10.80%	0.00%	8.10%	0.00%	2.70%	0.00%	2.70%	0.00%	73.30%	100.00%
4. 4. It is difficult to distinguish between Autism and Schizophrenia	2.70%	33.30%	5.40%	0.00%	27.00%	0.00%	27.00%	16.70%	35.10%	50.00%
5. 5. Autistic people do not show emotional attachments	0.00%	0.00%	21.60%	16.70%	21.60%	16.70%	32.40%	16.70%	24.30%	50.00%
6. 6. Autistic people do not show affectionate behaviors	8.10%	0.00%	10.80%	16.70%	13.50%	0.00%	27.00%	33.30%	37.80%	50.00%
7. 7. Most autistic people do not talk	5.40%	0.00%	13.50%	0.00%	8.10%	33.00%	29.70%	0.00%	43.20%	66.70%
8. 8. Most autistic people have special talents or abilities	40.50%	0.00%	27.00%	50.00%	21.60%	16.70%	8.10%	0.00%	2.70%	33.30%
9. 9. Most autistic people have intellectual limitations	8.10%	16.70%	16.20%	16.70%	40.50%	16.70%	32.40%	50.00%	2.70%	0.00%
10. 10. Most autistic people are more intelligent	8.10%	0.00%	37.80%	16.70%	40.50%	66.70%	10.80%	0.00%	2.70%	16.70%
11. 11. Autism exists only in childhood	5.40%	0.00%	5.40%	0.00%	2.70%	0.00%	2.70%	0.00%	75.70%	100%
12. 12. With proper treatment, autistic children will outgrow the disorder	8.10%	0.00%	16.20%	0.00%	16.20%	0.00%	29.70%	0.00%	29.70%	83.30%
13. 13. Autism is a developmental disorder	29.70%	33.30%	32.40%	16.70%	13.50%	16.70%	10.80%	0.00%	10.80%	16.70%
14. 14. Autism occurs more commonly among higher socioeconomic and educational levels	5.40%	0.00%	13.50%	16.70%	32.40%	16.70%	10.80%	16.70%	37.80%	50.00%
15. 15. Even with early intervention, prognosis for independent community functioning is not possible	2.70%	0.00%	13.50%	16.70%	8.10%	16.70%	27.00%	16.70%	48.60%	50.00%

In the *Completely Agree* (1) column, there were many improvements. Statement number one, “Autism is an emotional disorder”, went from 8.1 down to 0. This is a percent change of 100%. The same is true of statement 3, 6, 7, 8, 10, 11, 12, 14, and 15. Statement 2, “Emotional factors play a major role in the etiology of Autism”, went from 24.30 down to 16.70 a percent change of 31%. In the *Slightly Agree* (2) column, 5 statements also saw 100% percent change (3, 4, 7, 11, 12). Statement 10, “Most Autistic people are more intelligent” went from 37.8-16.7, a percent change of 55%. Column 3, *Neither agrees or Disagrees* will not be analyzed because it does not determine improvement or lack thereof in knowledge base, is difficult to differentiate if the participants showed a change or did not want to answer the question.

On the opposite end of the scale, responses 4 and 5 need to be looked at differently. In order to demonstrate improved knowledge, more people need to disagree with these sentences

than did on the pre-survey. Higher scores indicate a positive effect. In the *Slightly Disagree* column (4), improvements were seen. Statement 6, “Autistic people do not show affectionate behavior”, went from 27 up to 33.3, a percent change 23% and statement 14, “Autism occurs among higher socioeconomic and educational levels” went from 10.8 to 16.7, a percent change of 54%.

The *Completely Disagree* (5) column displayed the biggest improvement in knowledge level. Statement 3, “Autistic people are deliberately negative or non-compliant” improved from 73.3 up to 100 a percent change of 36%. Similar results were found in statements 5 and 11 which saw improvements in percent change of 35% and 33% respectively. Statement 5, “Autistic people do not show emotional attachments”, went from 24.3 of people who completely disagreed up to 50, This was a percent change of 134%. Statement 12, “With proper treatment, autistic children will outgrow the disorder”, went from 29.7 up to 83.3, a percent change of 180%. And finally, Statement #8, “Most autistic people have special talents or abilities”, improved from 2.7% to 33.3% a percent change of 1133%.

In addition to the statements on the Autism Knowledge Survey, there were two questions that asked how comfortable the participants felt caring for ASD patients and how likely they would utilize tools to help them provide the best care. These two questions were asked in a Likert scale manner. For the question, “How comfortable are you providing care to patients on the ASD spectrum?” the responses were ranked: (1) Extremely Comfortable, (2) Somewhat Comfortable, (3) Comfortable, (4) Slightly Uncomfortable, (5) Extremely Uncomfortable. For the question, “How likely are you to utilize tools or guidelines to help you care for the autistic patient?” The responses were ranked (1) Very Likely, (2) Somewhat likely, (3) Likely, (4) Unlikely, and (5) Very Unlikely. These questions showed improvement as well (Table 2).

Table 2. Comfort and Use of Guidelines

Questions	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey	Pre-survey	Post-survey
1. How would you rate your comfort level in caring for patients on the ASD spectrum	13.50%	16.70%	35.10%	16.70%	24.30%	66.70%	21.60%	0.00%	2.70%	0.00%
2. How likely would you be to use tools or guidelines to help you care for these patients	56.80%	33.30%	16.20%	16.70%	16.20%	50.00%	2.70%	0.00%	0.00%	0.00%

On question 1, the percentage of people that responded that were comfortable caring for this population went from 24.30 to 66.7; this equates to a percent change of 174%. Additionally, the percentage of those who were uncomfortable decreased from 21.6-0 and those extremely uncomfortable decreased from 2.7-0. Both equate to a percent change of 100%. On question 2, people who were likely to use tools or guidelines increased from 16.2 to 50, a percent change of 208%. Interestingly, the percentage of those who were *Very Likely* to use tools and guidelines decreased from 56.8-33.0, a percent change of 42%. Perhaps it can be assumed that the educational intervention increased their knowledge level and comfort and they no longer felt they needed assistance.

The results of the independent t-test are similar (Tables 3 and 4). In statistical analysis, the *null hypothesis* states there is no significant difference between specified populations, any observed difference being due to sampling or experimental error. The t-test shows statistically significant change. Except for question nine, all tests fell outside of the confidence intervals. With these results, the null hypothesis can be rejected, and the educational intervention has shown to have resulted in an improvement.

Table 3. Autism Knowledge Survey Independent T-Tests

Pre-Survey	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15
Mean	3.32	2.81	3.50	3.89	3.59	3.78	3.92	2.05	3.05	2.62	4.50	3.57	2.24	3.62	4.05
Standard Deviation	1.36	1.37	1.08	1.06	1.09	1.31	1.26	1.10	0.97	0.89	1.19	1.30	1.14	1.28	1.18
N	37	36	36	36	37	36	37	37	37	37	34	37	37	37	37
Variance	1.84	1.88	1.17	1.13	1.19	1.72	1.58	1.22	0.94	0.80	1.41	1.70	1.30	1.63	1.39
Confidence Interval	3.71-2.83	3.15-2.24	3.74-2.94	1.68-1.12	3.90-3.16	4.08-3.15	4.27-3.43	2.38-1.68	3.32-2.67	2.87-2.28	4.61-3.52	3.93-3.08	2.58-1.85	3.98-3.14	4.38-3.58
Post-Survey	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15
Mean	3.5	3	5	3	3.5	3.5	4	3.5	3	3.5	5	5	1	2.5	3.5
Standard Deviation	1.47	1.60	0.00	1.86	1.33	1.17	1.03	1.64	1.67	0.98	0.00	0.00	1.67	1.26	1.26
N	6	6	6	6	6	6	6	6	6	6	6	5	5	6	6
Variance	2.17	2.57	0.00	3.47	1.77	1.37	1.07	2.70	2.80	0.97	0.00	0.00	2.80	1.60	1.60
Confidence Interval	4.71-1.62	4.84-1.49	5.00-5.00	5.29-1.38	5.56-2.77	5.39-2.94	5.42-3.25	5.22-1.77	4.75-1.24	4.20-2.13	5.00-5.00	5.31-2.20	3.88-0.12	5.33-2.67	5.33-2.67
T-Tests	0.49	0.95	0.73	0.44	1.38	0.32	1.62	0.11	2	0.03	0.06	0.13	0.13	0.22	0.08

Table 4. Comfort and Use of Guidelines T-Tests

Pre-Survey	Q1	Q2	Post-survey	Q1	Q2
Mean	2.75	1.62	Mean	2.0	1.83
Standard Deviation	1.05	0.89	Standard Deviation	0.63	0.75
N	36	34	N	6	6
Variance	1.11	0.79	Variance	0.40	0.57
Confidence Interval	2.41-3.09	1.32-1.92	Confidence Interval	1.5-2.5	1.23-2.43
	Q1	Q2			
T-Tests	0.9	0.30			

Discussion

Autism Spectrum Disorder is very prevalent in our society. Current estimates reflect the incidence is roughly 1% of the population of the United States. These children who are diagnosed do not outgrow the disorder. They become adults who need health care services. According to the 2018 census, the city of Boston has 694,583 residents. If 1% of this number is considered, that is approximately 6,945 people with ASD. That same year, Brigham and

Women's Hospital saw 62, 521 emergency room visits and 35, 574 inpatient stays. Using that same formula, this equates to 625 and 355 possible adults with Autism.

Despite this fact, healthcare workers receive little to no education or training on how to care for this unique populace. As a result, ASD adults report lower patient satisfaction scores than their neurotypical counterparts. In addition, these adults utilize health care services 2.1 times more, have longer lengths of stay and worse outcomes. The Institute of Medicine has mandated that hospital care be patient centered, yet this has not been realized. Every patient should be given dignity and respect. They have a basic right to be listened to and involved in their care. It is imperative that their preferences and values are considered. It is impossible to provide this type of care when there is a knowledge deficit.

Nurses are in a unique position to accomplish this as they spend the most time with patients in the hospital setting. Providing education will help. Instead of a didactic class which are difficult to assess if learning occurred or if the material was retained, the creation of a nursing care guideline can help. This guideline is housed with the other documents nursing staff access on a regular basis in the *Nursing Clinical Practice Manual*. There are many advantages to this placement. First, the document is accessible in a place that is familiar to the staff. If it was placed in one of the other portals that the hospital keeps documents, it may not be used due to the lack of knowing it exists.

A second advantage is that it automatically becomes a document that is reviewed every two years for updates. Many great references have falling out of use due to the lack of incorporating new knowledge. A third advantage is that the document can be used quickly in the moment when a nurse admits one of these people or it can be used for research prior to an anticipated patient.

Interpretation

The study of the intervention demonstrated improvements in knowledge and comfort level in caring for these patients. The overall percent change was by far significantly improved for most questions. Although some of the results almost appear that the intervention had a deleterious effect, those numbers were skewed due to the limited number of post surveys. Additionally, the statistical data reinforces the positive results of the education. Fourteen of the fifteen questions in the survey showed statistically significant improvements. Therefore, it can be assumed that the development of the guideline for care was useful in increasing the knowledge base.

Limitations

There were a few limitations in this work. It would have been ideal to survey ASD patients after the staff utilized the tools. The lived experience would have been valuable in determining if the benefit to staff translated into benefit for the patients. Additionally, it would have also been beneficial to survey the staff after they used the tool. This way, it could also be learned if the guideline was helpful and if they perceived improved patient outcomes. Improvements could also be made to the work after researching these areas. Both would benefit from further study.

The lack of post-surveys was also problematic. It was important that the staff felt comfortable in answering the survey. There is a pervasive feeling in the hospital regarding a lack of trust in anonymous surveys. Many feel that the participant can be identified, and any information provided will be used in a malicious fashion. Because this is the known culture, it was imperative to have no identifiers. Even the question” *What is your role at BWH?* Was only answered by a few. Identifiers would have made follow up much more successful. There would

have been an opportunity to continually reach out to the staff to encourage a bigger post-survey sample size. Also, if identity was known, then perhaps a small monetary incentive for post participation could have elicited more effort. In addition, being able to identify participants so that tests could have been compared would have resulted in a more powerful statistical analysis by being able to use paired t-tests.

Conclusion

Although the study had a few flaws, the work overall was successful. Since there is currently little in the literature that gives information or guidance on how to care for adults on the autism spectrum, the work has been beneficial to the science. For nurses, who are the frontline workers and have the most time in patient interactions, the guideline will hopefully improve the patient care experience and decrease poor outcomes. It is hoped that this is just one of the first works to be developed and that this topic will continue to elicit more research for the betterment of this population.

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Appendix A

Autism Knowledge Survey (Cook, 1987)

What is your role at BWH?	RN	PCA	(please circle one)		
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Please rate on a scale of 1-5 <i>1 meaning completely agree</i> <i>2 meaning slightly agree</i> <i>3 neither agree nor disagree</i> <i>4 disagree slightly</i> <i>5 completely disagree</i>	
1. Autism is an emotional disorder	1 2 3 4 5
2. Emotional factors play a major role in the etiology of autism	1 2 3 4 5
3. Autistic people are deliberately negative and non-compliant	1 2 3 4 5
4. It is difficult to distinguish between autism and schizophrenia	1 2 3 4 5
5. Autistic people do not show emotional attachments	1 2 3 4 5
6. Autistic people do not show affectionate behavior	1 2 3 4 5
7. Most autistic people do not talk	1 2 3 4 5
8. Most autistic people have special talents or abilities	1 2 3 4 5
9. Most autistic people have intellectual limitations	1 2 3 4 5
10. Most autistic people are more intelligent	1 2 3 4 5
11. Autism exists only in childhood	1 2 3 4 5
12. With proper treatment, most autistic children will outgrow autism	1 2 3 4 5
13. Autism is a developmental disorder	1 2 3 4 5
14. Autism occurs more commonly among higher socioeconomic and educational levels	1 2 3 4 5
15. Even with early intervention the prognosis for independent community functioning is not possible	1 2 3 4 5

Please rate on a scale of 1-5 <i>1 extremely comfortable</i> <i>2 somewhat comfortable</i> <i>3 comfortable</i> <i>4 somewhat uncomfortable</i> <i>5 extremely uncomfortable</i>	
1. How would you rate your comfort level in caring for patients on the autistic spectrum?	1 2 3 4 5

Please rate on a scale of 1-5 <i>1 very likely</i> <i>2 somewhat likely</i> <i>3 likely</i> <i>4 somewhat unlikely</i> <i>5 very unlikely</i>	
2. How likely would you be to use tools or guidelines to help you care effectively for autistic patients?	1 2 3 4 5

Appendix B

Autism Accommodation Tool

1. In general, how would you best describe your (their) ability to understand what people say?
 - a. I (he/she) can understand spoken language well
 - b. I (he/she) often has a hard time understanding or processing what people say
 - c. I (he/she) understands very little spoken language
 - d. My (his/her) ability to understand spoken language changes so much. Depending upon the situation, that I cannot put into one of these categories
2. In general, how would you describe your (his/her) ability to speak?
 - a. I (he/she) can speak well
 - b. I (he/she) can speak but often has a hard time saying what I (he/she) wants to say
 - c. I (he/she) has a very hard time speaking (for example can only use short phrases)
 - d. I (he/she) has no ability to speak
 - e. My (his/her) ability to speak changes so much, depending on the situation, that I cannot put it into one of these categories
3. How would you describe your (his/her) ability to read?
 - a. I (he/she) cannot read
 - b. I (he/she) can read some words and short sentences
 - c. I (he/she) can read at a basic level
 - d. I (he/she) can read at a high school level
 - e. I (he/she) can read at college level
4. How would you describe your (his/her) ability to write?
 - a. I (he/she) cannot write or type
 - b. I (he/she) can write or type a little bit
 - c. I (he/she) can write or type at a basic level
 - d. I (he/she) can type at a high school level
 - e. I (he/she) can type at a college level
5. What types of alternatives to speech do you (he/she) use if any?
 - a. Text-based alternatives to speech (AAC *alternative and augmentative communication*, typing, written notes, iPhone app)

- b.* Picture based alternatives to speech (picture based AAC, picture boards, drawing)
 - c.* American sign language
 - d.* Other signs, gestures, or behaviors
 - e.* None
- 6. What can his healthcare providers do to help you (her/him) understand them better?
 - a.* Use simple words and short sentences
 - b.* Use very precise language even if it means using longer sentences or advanced vocabulary
 - c.* Be very concrete and specific
 - d.* Show diagrams or pictures or models whenever possible
 - e.* Use medical words
 - f.* Avoid medical words
 - g.* Ask you (him/her) to repeat what is said in their own words
 - h.* Write down important information or instructions
 - i.* Give very detailed information
 - j.* Focus only on the most important information
 - k.* Be patient if you (he/she) needs to ask a lot of questions
 - l.* Give you (him/her) extra time to process what you have said and check to see if you are ready to move on
 - m.* Do not try to talk to you (him/her) while there are other noises (example beeping, outside noises, people talking)
 - n.* I (he/she) doesn't need help to understand providers
 - o.* I need (he/she) needs accommodations to help me understand providers but they are not listed here
- 7. What can your (his/her) healthcare providers do to help him answer questions or give information?
 - a.* Ask very specific, concrete questions and avoid broad questions
 - b.* Ask mostly yes and no questions when possible
 - c.* Give you extra time to respond to questions
 - d.* Read written notes that you (he/she) prepares ahead of time
 - e.* Give examples of the types of things people may experience and let you (him/her) tell you if they experience this too
 - f.* Show you (him/her) a list of symptoms to choose from
 - g.* Help you (him/her) answer questions about time linking to important events in your (his/her) life
 - h.* Offer to reword the question if you (he/she) seems confused
 - i.* Remind you (him/her) that it is ok to not know the answers to the questions

- j.* Remind you (him/her) that it is ok to not be 100% exact in your (his/her) answers
 - k.* I (he/she) does not need accommodations to answer questions or give information
 - l.* I (he/she) need accommodations to answer questions that are not listed here
8. What do you want your (his/her) healthcare provider to know about your (his/her) communication?
- a.* I (he/she) may have a hard time communicating even if my (his/her) speech sounds fluent
 - b.* I (he/she) can be involved in decisions about care even though I (he/she) have difficulty speaking
 - c.* I (he/she) often takes language too literally
 - d.* In general, I (he/she) can read better than understand spoken language
 - e.* I (he/she) may have difficulty understanding tone of voice, facial expressions, or body language
 - f.* My (his/her) ability to communicate changes a lot depending on the situation
 - g.* If I (he/she) seems rude, I (he/she) don't mean it. I'm (he/she) just direct
 - h.* I (he/she) have a hard time using the telephone
 - i.* There isn't anything related to my (his/her) communication that my (his/her) providers need to be aware of
 - j.* There are things related to my (his/her) communication that my (his/her) providers need to be aware of but they are not listed here



Appendix C

Brigham and Women's Hospital
Department of Nursing

Nursing Care Guideline for Care of the Adult Patient on the Autism Spectrum

Guideline Name:	Care of the Adult Patient on the Autism Spectrum
Guideline Number:	GUIDE_35
Contact person(s):	Medical/Surgical PDMs
Effective Date:	01/23/2020
Approved By:	Standards, Policies and Procedures Committee 12/19/2019 Nurse Executive Board 01/23/2020
Personnel Approved for:	RN, LPN, Unlicensed nursing personnel (e.g., PCA, ESA,)
Location(s) Approved for:	Intermediate Care, Critical Care, Perianesthesia, Emergency Dept.

Keywords: ASD, Asperger's, cognitive impairment, communication, information processing

- I. **Introduction:** Number of patients worth a diagnosis of Autism Spectrum Disorder (ASD) is increasing. The current prevalence is 1:59 or roughly 1% of the U.S. population. There is great heterogeneity between patients in regard to communication strengths, challenges, and styles. There are also large differences between receptive and expressive communication as well. Stressors can also alter this level of communication such as a hospital visit or admission. For example, a patient who speaks fluently during a normal visit may not be able to use speech in an emergency or over stimulating environment.
- II. **Purpose:** People with ASD do not outgrow the disorder. Many of our patients have a diagnosis of ASD/Asperger's and most health care workers have had little to no training in how to care for the unique needs of this population. The purpose of this guideline is to provide some baseline information on ASD and some strategies that may help improve the patient care experience.
- III. **Rationale:** ASD patients are frequent users of healthcare. They have reported longer lengths of stay and decreased satisfaction. These patients often have a difficult time with emotional regulation in response to stressors and if not understood can cause behavioral challenges. It is necessary to develop a patient-centered approach to care to ensure they do not experience unnecessary harm or treatments.

Please Note: These are intended to be used as best practice guidelines. Appropriate care should always be based on the clinical picture.

Overview

Autism Spectrum Disorders present differently in each patient. It is called a spectrum because one may have strengths in one area but lack capability in another. This leads to a variety of confusion and bias when caring for these patients. Below is the latest definition as defined by the American Psychiatric Association.

1. Persistent deficits in social communication and social interaction across multiple contexts. (Diagnosis requires the person meets all three criteria.)
 - a. Deficits in social-emotional reciprocity
 - i. Difficulty initiating or sustaining back and forth conversation; tendency to monologue without attending to listener cues; unusual response to greetings or other social conventions.
 - b. Deficits in nonverbal communicative behaviors used for social interaction
 - i. Lack of eye contact; difficulty understanding non-verbal communication; an unusual tone of voice or body language.
 - c. Deficits in nonverbal communicative behaviors used for social interaction
 - i. Challenges adapting behavior to match different social settings such as when interacting with family, friends, authority figures, or strangers; difficulty developing or sustaining friendships; greater than usual need for time alone.
2. Restricted, repetitive patterns of behavior, interests, or activities. (Diagnosis requires person meets at least two of four criteria.)
 - a. Stereotyped or repetitive motor movements, use of objects, or speech
 - i. Repetitive movements or "stimming" (e.g., rocking, flapping, pacing, or spinning for enjoyment or as a coping mechanism); arranging objects in a very precise manner; echolalia; continuously repeating sounds, words, or phrase
3. Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behavior
 - i. Greater than expected degree of distress with changes in routines or expectations; difficulty transitioning between activities; need to do the same thing in the same way each time; greater than usual reliance on rituals for accomplishing daily tasks.
4. Highly restricted, fixated interests that are abnormal in intensity or focus
 - i. Intense special interests (e.g., looking at spinning objects for hours, learning the detailed schedules of an entire public transportation system, or becoming an expert in weather patterns) while having significant difficulty attending to topics outside of one's areas of special interest.
5. Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment

- i. Being hyper- or hypo-sensitive to sounds, lights, smells, or textures; having an abnormally high or low pain threshold; difficulty processing more than one sense at a time (e.g., not being able to understand spoken language while looking at someone's face); tendency to become confused or overwhelmed by sensory stimuli; challenges with body awareness or separating different types of sensations
6. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)
 - i. Though characteristics should have been present throughout one's lifetime, a change in circumstances can disrupt coping strategies and make characteristics more pronounced; alternatively, environmental facilitators, supports, and coping strategies may make characteristics less noticeable.
7. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level

Since there are many presentations and interventions that can be utilized, it is important to get a base line understanding of the patient's capabilities. The below information has been directly obtained from the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) funded by the National Institute of Mental Health:

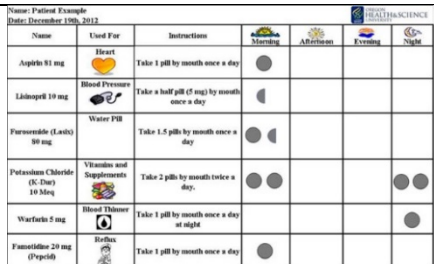
<i>Alteration in Communication</i>	
<ol style="list-style-type: none"> 1. Have the patient or their caregiver fill out the <i>Autism Accommodations Tool</i> Autism Accommodation Tool.docx This tool determines: <ul style="list-style-type: none"> • Patient's ability to understand spoken language. • Patient's ability to speak. • Patient's ability to read and write. • Patient's use of alternative and augmentative communication (AAC). AAC may include picture-based systems (e.g. picture boards), text-based systems (e.g. text-to-speech programs), sign language, or other signs or 	<p>Understanding a patient's communication needs, strengths, and preferences is very important. Patients on the ASD spectrum attribute many failed healthcare interactions to providers' assumptions, misunderstanding of their strengths or challenges, or the fact that the communication did not occur using the most effective method.</p>

<p>behaviors. They may be stand-alone devices, programs on computers, tablets, smartphones, or informal systems (e.g., picture cards, notes on a piece of paper).</p> <ul style="list-style-type: none"> • Patient's preferred mode of communication. • Degree to which communication normally varies based on environmental factors or stress. 	
Literal and Precise Language	
<p>1. It is common for those on the spectrum to take language literally. It is also common for those on the spectrum to require very precise language.</p>	<p>Ex. <i>“They asked him on a scale of 1-10 where is your pain. First time he answered. How do you weigh pain? I don’t weigh my pain.”</i></p>
<p>2. Patients may also feel anxiety because they do not know how to answer a question with complete accuracy.</p>	<p>Ex. <i>“Do you have chest pain?”</i> a patient may feel they need to think back on every day of life to make sure they have never felt chest pain before. They may also not be able to answer how frequently something happens because the symptom isn’t constant.</p>
Nursing Interventions	
<ul style="list-style-type: none"> • Be very concrete and specific • Avoid figurative expressions and figures of speech • Avoid broad questions: yes and no may be most appropriate • Show patients lists of symptoms from which to choose • Give examples of the types of things people may experience, and have the patient tell you if he also experiences them • Remind patients that it is OK if they do not know the 	

<p>answers to questions or are not exact in their answers</p> <ul style="list-style-type: none"> • Give patients very direct and concrete examples when discussing your assessment and plan • Direct patients to detailed information or resources about their health conditions and treatment options 	
Non-Verbal Communication	
<p>1. Patients may have difficulty understanding tone of voice, facial expressions, or body language. They may inadvertently seem rude due to their atypical body language or facial expressions.</p>	<p>Ex. <i>“Talking to people doesn’t come naturally to me. I have a lot of difficulty with open ended questions and a lot of trouble understanding other people especially if there is any background noise or if they are misreading me or my face and then react to me. I get that a lot. People somehow think I am being rude or deceiving them or being manipulative for no reason that I can see. So, they tend to get more aggressive with me.”</i></p>
<p>2. Eye contact. Patients on the spectrum often avoid eye contact. Do not force a patient to make eye contact, because it may be uncomfortable or may hinder his/her ability to communicate effectively.</p>	<p>Ex. <i>“Don’t assume no eye contact means we are not listening, or we are being deceptive. It is often a way we need to behave to regulate incoming stimuli and not be overwhelmed by too much at once.”</i></p>
<p>Point of Emphasis</p> <ul style="list-style-type: none"> • Patient’s may make repetitive motions called “stimming” Stimming can be an effective coping mechanism especially during times of stress. Do not assume the patient is distracted or inattentive just because they are fidgeting or making repetitive movements 	<p>Ex. Hand flapping, rocking, pacing, jumping</p>
Processing Speed and Real-Time Communication	
<p>1. Many individuals on the autism spectrum have difficulty processing information quickly or communicating in real time</p>	<p>Ex. <i>“It might take a while for a patient to effectively communicate. It takes them a little bit extra amount of time to process questions, process information, and sometimes their responses are, you know, gonna be more delayed than say the typical patient’s might.”</i></p>

<p>2. Processing speed may interfere with healthcare communications in multiple ways.</p> <ol style="list-style-type: none"> Patients may not be able to process language or information quickly enough to respond to questions or make healthcare decisions They may not be able to process stimuli rapidly. For example, during an exam, a patient may not be able to indicate that an area is tender before the provider has started palpating a different area 	<p><i>For instance, if the patient receives questions or information to describe or identify their condition or symptoms, they might not be able to answer right there. They might sort of need time to think it over and answer the next time.</i></p>
<p>Nursing Care Interventions</p>	
<ul style="list-style-type: none"> Give patients time to process what has been said or to answer questions Check to make sure they are ready to move on Give patients extra time to process things they need to see, hear, or feel before they respond Encourage patients to prepare notes for their questions Write down important information or instructions so that they can review them later 	
<p><i>Alteration in Comfort</i></p>	
<p>1. Patients on the spectrum commonly have atypical sensory processing. This may take the form of increased or decreased sensitivity to sounds, lights, smells, touch, or taste. They may have great difficulty filtering out background noise, processing information in over-stimulating environments, or processing more than one sensation at a time.</p>	<p><i>Ex.” The lights in the room are very bright and that is exacerbated by the white walls. Sometimes the waiting rooms are crowded, and I cannot filter out the background of people talking. I feel disoriented by being led down long hallways to different rooms. I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions.”</i></p>
<p>Nursing Interventions</p> <ul style="list-style-type: none"> Use natural light, turn off fluorescents or make lightening dim. 	

<ul style="list-style-type: none"> • Try to place patient in a quiet room if possible • Avoid multiple bed assignment changes • Have only one person talk at a time and try not to talk while other noises are present • Be mindful of beeping pumps, loud talking, and other machines in and outside of the room • Avoid unnecessarily touching the patient (for example, to express concern) • Warn the patient before you touch them • Encourage the patient or supporters to bring objects to reduce or increase sensory stimuli 	<p>Ex. Headphones, sunglasses, hats, stress balls, gum, soft fabric</p>
Body Awareness, Pain, and Sensory Processing	
1. Many ASD patients experience challenges related to limited body awareness	<p>Ex. discriminating abnormal from normal body sensations, difficulty pinpointing the location of a symptom, difficulty characterizing the quality of the sensation, particularly low or high pain thresholds, and difficulty recognizing normal stimuli such as hunger or the need to urinate.</p>
2. Patients describe situations where issues related to body awareness caused providers to make incorrect medical assessments	<p>Ex. <i>“I don’t know my own body. So, when I feel all these different sensations, everywhere, I don’t know which is the real problem and which is just a sensation”</i></p> <p><i>“The problem is it difficult for me to isolate specific sources of pain and identify duration and intensity. It is sort of like the equivalent to white noise”</i></p>
Nursing Interventions	
<ul style="list-style-type: none"> • Ask patient or caregiver how the patient best describe their feelings and experiences • Use scales or pictures that reflect the sensation 	

<i>Alteration in Cognitive Functioning</i>	
1. Consistency	Ex. ASD patients may become confused or anxious by changes in routine. This may lead to meltdowns or an inability to function
Nursing Interventions <ul style="list-style-type: none"> Try to have consistent caregivers Attempt to stick to schedule as much as possible Give warning early if there will be a change in the plan for the day 	Ex. If the patient always has lunch at 12pm, make sure he has lunch at that time
2. Time Awareness	Many patients report difficulty with concepts related to time. This may make it difficult to answer questions about onset, duration, or frequency of symptoms or illness. It may also make it difficult to follow time-based instructions
Nursing Interventions	
<ul style="list-style-type: none"> Help the patient answer questions about time by linking to important events Work with the patient to explain time-based recommendations 	Ex. Set an alarm when to take a pill, or link pill taking to a specific part of the daily routine (take with breakfast)
3. Visual Thinking-some individuals on the spectrum “think in pictures. It may be easier for them to understand information and make decisions if visual aids are used	Ex. Patients who have fluent speech may still have stronger visual processing than auditory processing skills
Nursing Interventions	
a) Offer to use diagrams, pictures, or models b) Create visual schedules with recommendations	
Planning, Organizing, and Sequencing	
Many people on the spectrum have difficulties with planning, organization, and sequencing. These	Ex. “It’s like having a list of a hundred things you have to get done right away, which you must memorize aurally in the five minutes you

challenges can have significant impacts on the patient's ability to navigate the healthcare system	<i>spend with the doctor and then execute without error, even though you don't even understand how to do half the things you need to do"</i>
Nursing Interventions <ul style="list-style-type: none"> • Write out a detailed step by step instructions • Show/demonstrate to patients what you want them to do • Give patients worksheets or diaries to keep track of symptoms/tasks 	
Exams and Procedures	
Nursing Interventions <ul style="list-style-type: none"> • Explain what is going to be done before doing it • Show the patient the equipment or a picture of the equipment before using it • If possible, do a trial run of difficult exams or procedures • Tell the patient how long an exam or procedure is likely to take • Warn the patient before touching or doing something to them • Limit the amount of time the patient must be undressed or in a gown • Give patients extra time to process things they need to see, hear, or feel, before they respond • Let the patients give you a signal to tell you they need a break • Ask the patient from time to time if they can handle the pain or discomfort 	In many cases, thoughtful planning and appropriate accommodations can enable patients to tolerate examinations and procedures that have previously been intolerable. Nevertheless, there may be times when anesthesia may be needed to tolerate exams or procedures
Phlebotomy	
1. Lab draws can be particularly challenging for some on the ASD spectrum. If a patient has	

<p>a known hard time, follow the tips below:</p>	
<p>Nursing Interventions</p> <ul style="list-style-type: none"> • Speak to the LIP regarding only necessary tests and plan to group them together whenever possible • Allow the patient to lie down or lean back on something • Give the patient a very detailed explanation of what will happen, including how many tubes of blood will be filled • Consider giving an anti-anxiety medication before the blood draw • Give the patient plenty of warning, so he/she can prepare themselves emotionally • Give the patient something to distract their attention 	
<p>Alteration in Coping</p>	
<p>1. Patients on the ASD spectrum have a difficult time with emotional regulation. Emotions are an abstract concept and not easy to process. Internal signals are not linked to the emotional experience. Since they don't know how to feel, it is hard to control emotions.</p>	<p>Ex. <i>"When I become overstimulated, it feels lots of different things. Sometimes, it comes in the form of a panic attack. I'll get to feel really hot, and then my head may start to hurt, and I may start to feel sick. And sometimes, I'll feel like ants are crawling on my skin, or like I've just lost touch with my body."</i></p>
<p>2. The Rage Cycle-50% of people with ASD experience the rage cycle. This cycle has 3 parts</p> <p>a. <i>Rumbling</i>-This is the beginning of the cycle. A person may start to display some stimming behavior to try and stay calm or start to manifest signs of increased anxiety. This is the best time to intervene. 75-80% of meltdowns can be avoided if they can be calmed.</p>	<p>a)indicators that a person is getting upset include:fidgeting, swearing, making noises, inappropriate giggling or laughter, tapping feet, changing voice volume</p> <p>b)Rage may manifest as yelling, kicking, screaming, throwing things. It may also</p>

<p><i>b. Rage-</i> time of uncontrolled emotions. Do not try to console. Make sure they are in a safe place and let the event ride out. Staff should visually watch but keep distance. Interaction now will increase the time the event lasts.</p> <p><i>c. Recovery-</i>time to regroup and regulate. This is the time most vulnerable to revert into rage. Do not engage unless initiate by the patient. Give him/her space and time</p>	<p>manifest as quiet, shutdown and disconnected, not responding to dialogue</p> <p>c)May want to rest, sleep or withdraw for a while</p>
<p>Nursing Interventions</p> <ul style="list-style-type: none"> • Find out from patient or caregiver what things may precede a rage cycle • Ask about what methods are used to calm the patient when experiencing anxiety/stress • If the patient cannot be consoled allow time for the event to happen. It is important to keep the patient and the staff safe. 	<p>Points Of Emphasis</p> <ul style="list-style-type: none"> a. It is critical to listen to the patient an/or caregiver. They are the best source of truth. They know the patient much better than the care team. b. Techniques may include breathing, counting, visualization c. Keep the number of people in the room to a minimum. Less is best. The more people, the more stimuli. Avoid restraints if possible. This will make the situation worse
<p>Safety</p>	
<p>1)Because the ASD patient may have challenges with emotional regulation along with excessive stimuli that may increase anxiety-safety is a concern.</p> <p>2) If the patient starts to get upset and calming techniques are not working, then call a Safe Response or Code Gray</p>	<ul style="list-style-type: none"> a) Consult the Psychiatric Nursing Resource service if there is any concerns around safety (just because a patient has ASD does not mean they are violent. But this must be considered on an individual basis with each patient) b) This will allow for everyone to be on the same page and ensure consistency in care that will decrease or eliminate these episodes <p><i>Remember: The safety of the staff and patient take priority</i></p>

Quick Reference Guideline to Care	
Have patient or caregiver fill out <i>the Autism Accommodation Tool</i>	No two people with Autism are alike. This tool can guide how to care for the patient effectively
Decrease stimuli-lights, noises, clutter, smells may increase anxiety	Use low lights, close doors, control smells as much as possible (use CVM if patient cannot be left in a closed room)
Avoid unnecessary touch	Some patients with ASD cannot tolerate being touched-this increases anxiety
Approach the patient calmly and slowly, leaving distance between you and the patient	
Explain all procedures and tests prior, if possible, show the patient what you are going to do before you do it	ASD patients need to be able to prepare mentally for change
Provide simple explanations using basic terms	ASD patients interpret language literally, do not use jargon or slang
Ask Yes/No questions rather than abstract or multi-step questions	
Allow patient time to process and respond to questions	ASD patients may have difficulty with processing information and may require more time
Avoid chit chat unless the patient engages you	Many ASD patients have challenges with social interactions and finds unnecessary conversation stressful
Patient may not maintain eye contact or respond to questions-this does not mean they are not listening	Many ASD patients do not recognize social cues or non-verbal body language; you may need to ask them if they understood what you have said
Reassure the patient that you are here to help them	
Provide an appropriate structured and soothing environment	Many ASD patients need structure to avoid an increase in anxiety
Have consistent staff and minimize change when possible	
Cluster care when able	Multiple interruptions may increase anxiety
Speak with LIP about limiting lab draws and unnecessary testing	Phlebotomy can be particularly challenging for this population
Use de-escalation techniques when necessary	Deep breathing, counting, visualization-ask the patient or caregiver what techniques work best
Use warm blankets or if not available, multiple blankets to help calm the patient	Avoid restraints <i>Like infants who have undeveloped nervous systems, ASD patients have a heightened</i>

	<i>response to stimuli and will calm with wrapping or weight</i>
Read the guideline above for help and if more information is required - consult the Psychiatric Resource Service	
Understand that uncontrolled anxiety can lead to meltdowns and rage	Do not hesitate to call Safe Response or Code Grey-safety of the staff and patient is the top priority

Approval Listings:

Approved By: Standards, Policies and Procedures Committee 12/19/2019

Approved By: Nurse Executive Board 01/23/2020

Appendix D

Cost Benefit Analysis

ASD adults are 2.1 more likely to access healthcare services than their neurotypical counterparts (Mason, et al., 2019), and have longer lengths of stay (Carter, et al., 2017). Since it has been shown to be difficult to extract data that shows the number of patients on the ASD spectrum admitted as an inpatient or treated in the emergency department, the national prevalence of ASD will be used to demonstrate the approximate number of ASD patients cared for at Brigham and Women's Hospital in the year 2018. The national prevalence of ASD is 1% of the total population. In 2018, the hospital had 62,521 emergency department visits and inpatient stays.

2018 BWH Data		1% Population Prevalence
Emergency Department Visits	62, 521	625
Inpatient Stays	35, 514	355

The literature has shown that ASD patients have more emergency room visits and longer lengths of stay. Reducing just one day of admission can reduce costs by a significant amount.

Average cost of one inpatient stay = \$2715

Number of days saved in one year = 355

Cost x days = \$963,825

There was minimal cost associated with the intervention. The nursing care guideline was created by the author on her personal time. Time spent will count as some of the 500 clinical practicum hours required to attain the Doctorate of Nursing Practice degree. The only cost incurred will be in completing the pilot of the guideline. The pilot will involve a half hour in-service which in turn will create a salary cost of the time needed to attend the educational training.

Average salary of RN on Tower 14ABCD = \$60

Average salary of PCA on Tower 14ABCD= \$18

Therefore if we are aiming at 75% of each job role than costs will include:

Job Role	Estimated Average Salary	Number of staff	75% of staff	Total cost of job role
Registered Nurse	\$ 60	130	97	\$5820
Patient Care Assistant	\$ 18	50	38	\$900
				Total Cost \$6720

Since the overall cost of the intervention is \$6720, and the savings could be \$963,825, the benefit far outweighs the cost. In addition, it is hoped that there will also be non-monetary benefits associated with the intervention such as an improved patient/family experience and the improved likelihood of these patients returning to the facility for care.